

Participatory video and dementia

Outline of a research project
funded by the NIHR School
for Social Care Research



Improving the evidence base for
adult social care practice

Can participation in making video films enhance social inclusion and well-being for people with dementia in care homes?

Research suggests that the deterioration over time associated with dementia is made worse by a lack of social interaction and meaningful activity. Evidence is also growing that reducing the psychological ill-being related to a diagnosis of dementia can lower the costs of care in the longer term. A positive impact may therefore be achieved through measures to enhance social participation and activity levels, particularly in residential care homes where older people are prone to social exclusion.

One such approach is to facilitate people with dementia in institutional care to make films using Participatory Video (PV). PV allows people with dementia to take an active part in making the films, rather than just being filmed by someone else. They decide what the films should be about and how they are made, assisted by care home staff. A pilot PV project for people under 65 with dementia in a day centre found that participants enjoyed taking part and that it increased self-esteem.

This project

- will explore the benefits of an adapted form of Participatory Video (PV) for people over 65 with dementia living in long-term social care accommodation.

It aims to

- work with people with dementia to create a suite of short films using a form of PV that is responsive to individual abilities, interests and preferences
- evaluate the impact of PV on social inclusion, meaningful activity, and well-being
- identify the perceived cost-benefit implications for the social care provider site involved
- consult participating care/support staff and family members in order to identify strengths and limitations for future work
- teach basic PV principles and techniques to care/support staff and family members to ensure sustainability of the approach
- secure opportunities for screenings of the films produced, and the widest possible dissemination of a training DVD of the PV process.

Research project outline

WHAT IS THE CONTEXT?

Social care is intended to involve more than just meeting the basic physical needs of people who have dementia; it should also maintain or enhance their quality of life and well-being, including emotional well-being and self-esteem. Yet people with dementia find that following diagnosis they feel stigmatised, set apart from the rest of society, and excluded from making decisions affecting their own lives. This can lead to loss of self-esteem, depression, and loss of personal control.

The Department of Health says people with dementia should receive high-quality care and equal quality of care wherever they live. However, activities provided in residential care – where dementia is commonplace – are sometimes based on stereotypical ideas about what older people enjoy, rather than on their personal interests and preferences. As a result, people with dementia can become bored, frustrated and anxious and this may produce reactions that are seen by staff as 'challenging behaviour'.

While recognising that service user involvement for people with dementia presents additional practical and ethical challenges, it is nevertheless possible to address these issues. Participatory video is one such strategy (see Box). PV provides a rare opportunity to present the 'voices' of people with dementia, in contrasting with the common tendency for audio-visual material to focus exclusively on the experience of dementia, from diagnosis onwards, rather than on the whole person.

In 2009, this approach was piloted at a voluntary sector day centre with people with early onset dementia (i.e. those under 65 years). This was the first dedicated use of PV with people who have dementia, and it found that there was considerable enthusiasm, particularly among those clients whose cognitive difficulties made it harder for them to take part in existing activities such as bingo and word games. The results suggested that PV had the potential to enhance self-esteem and encourage social inclusion for this client group. At the same time,

Participatory video (PV)

PV is an innovative approach to film-making which involves socially excluded, disenfranchised or marginalised groups in making films about issues of concern to them:

- PV means that the people with dementia take an active part in making films, rather than just being filmed by someone else;
- They are able to decide what the films should be about, and how they are made. This may involve telling a story that is filmed, using a film-camera, or directing the action;
- The staff of the residential home are also involved;
- PV can be adapted for people with dementia to allow each person to take a part in the film-making process on his or her own terms, according to their individual choices, abilities and interests;
- The participants decide whom they wish to see the film.

it became apparent that adaptations were needed to the standard PV process, placing less emphasis on the technicalities of film-making, and these changes were made to allow the technique to be used meaningfully with dementia.

This project will extend the use of PV to people over 65 in residential social care in order to assess its impact on social inclusion, meaningful activity and well-being among this group.

HOW WILL THE PROJECT WORK?

Over a period of 18 months, researchers will work with 15 participants with dementia aged over 65 living in residential social care and six care practitioners/carers to create a suite of low-cost short films representing the service users' perspectives and concerns. Care staff and any family members involved will learn how to use the PV process so that they can carry on once the project has ended.

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STAGE 1: Recruitment of participants

Participants will reflect the heterogeneity (age, gender, social class, and ethnicity) of people with dementia currently receiving social care services in England. Locating the study in long-term residential social care, and including older people who have more profound cognitive problems, will involve those groups of people with dementia who are still routinely excluded from mainstream service user involvement initiatives. Participants will, however, self-select for inclusion. In addition to the researchers, each of the three PV groups will include at least one member of the care staff and at least one family member or volunteer.

STAGE 2: Film making and assessment

A 'repeated measures' design will compare social inclusion, meaningful activity and well-being before and after the PV experience.

- One week before the intervention begins, the research assistant and/or care staff will conduct baseline measures of occupational diversity, social involvement and well-being during the time period for which the intervention is planned (e.g. 2–4pm on a Wednesday) based on whatever activity the participant happens to be involved in at the time. Standard profiling tools will be used.
- Participants will be divided into three groups. Three sessions will be held with each to include discussion of film content, image searches, and storyboarding etc. Baseline measures will be repeated in order to ascertain any benefits of group involvement *per se*, which are not directly related to participating in video-making. At least one of the three sessions will be filmed for each group in order to record the process and levels of engagement.
- Three 'pure PV' sessions will be delivered for each group to include camerawork, direction, editing and viewing of completed films. Again, at least one session for each group will be filmed in order to record the PV process and levels of engagement.
- Summative measures of occupational diversity, social involvement and well-being for each participant will be taken during the time period in which the intervention took

place, and one week after it has ended. The latter is in order to ascertain whether any enhanced self-esteem, social confidence, and improved levels of interaction and life history awareness (the latter on the part of staff) are sustained beyond the lifetime of the PV intervention.

- Repeat measures of well-being will be taken when participants are watching the films they have been involved in making. This is to assess whether well-being is more apparent when watching films than at the time of pre- or post- intervention measures.

The film footage recording the PV process will also be analysed for indications of well-being and ill-being during participation, and for any notable exemplars of social involvement or exclusion. The footage will be edited to produce an instructional video which can be used to disseminate the PV approach to the care sector generally

STAGE 3: Focus groups

All staff, family members and volunteers involved in the PV group sessions will take part in an end-of-project focus group in order to ascertain: their experience of the process; their view of the value of PV for increasing social involvement and well-being for people with dementia; their views on its feasibility from a cost-benefit perspective, and their degree of confidence in continuing to use the approach. The aim of the focus groups is to ascertain the appropriateness and cost-effectiveness of the adapted form of PV for this client group in comparison with other activities, or inactivity.

Project publications

The findings will be disseminated through a variety of routes to reach a wide audience. Researchers will co-author at least one article for an academic peer-review journal, and one article for a professional/practice journal. Among other outlets, the project findings will be presented at a practice conference, one SSCR conference and one academic conference, will be presented to relevant local Social Services departments and published on a number of online networks. Broadcast opportunities will be sought for the short films produced by participants.

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HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

This research project directly tackles the question: How can adult social care most cost-effectively contribute to meeting 'higher order' outcomes such as social participation and well-being for different user groups? It also sits well with the current personalisation agenda in social care, the National Dementia Strategy for England's emphasis on transforming quality of care, and contributes towards plans for 'digital inclusion' in the public sector generally.

PV has considerable potential as a method for facilitating service-user involvement among harder-to-engage groups such as people with dementia, and has the potential for breaking down traditional barriers between people with and without dementia.

The project potentially has relevance to a much wider constituency of carers and practitioners through the distribution of the short films, and a DVD which can be used in staff training and development. The adapted PV process has potential for use with other groups of service users in adult social care such as people with learning disability, physical incapacity or sensory impairments.

The Research Team

The research team are members of Bradford Dementia Group (BDG), at the University of Bradford's School of Health Studies. BDG has a significant record in the development of strategies for meaningful service-user involvement for people with dementia.

Dr Andrea Capstick, Lecturer in Dementia Studies, leads the project with responsibilities including recruitment and site selection, analysis of data and authorship of the final report. She has previous experience of piloting PV in a social care setting, is a member of the Committee for Ethics in Research at the University of Bradford, and her Doctorate was based on use of film with Dementia Studies students.

Dr John Chatwin, BDG Research Fellow on the Yorkshire Film Archive project involving people with dementia, has a background in film as research methodology, cognate research involving older people, progressive conditions, palliative care and non-pharmacological interventions. He will lead in the film-making processes, editing and post-production and has recent experience of two studies using PV with people with dementia.

Dr Katherine Ludwin who is the research assistant on this project, has previously been employed on an ESRC-funded study on decision making in dementia at the University of Bradford.

Project title:
Can Participatory Video (PV) enhance social participation and well-being for people with dementia in residential social care?

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